

# Developmental Disabilities Awareness Month

Human services March 1, 2023

Good Morning! Thank you for this opportunity to speak with you.

I am a parent of a middle age adult daughter who has autism, a lifelong disability. I belong to a group of over 100 advocacy parents called the Developmental Disabilities Housing Initiative who are working on the development of housing options for their children. There are more families in Vermont who also need help with this but are physically, emotionally and, frequently financially exhausted providing care to their loved one. You may never hear from these families due specifically to these situations. Our population is aging and we would like to be sure our family members, who are particularly limited in their ability to express and protect themselves, have the permanence, security, and stability they deserve throughout their lives.

My daughter will never grow out of this condition called autism and we, her parents, will someday no longer be there for her. For some reason we continue to age even though we still think we are 35!

We thank you for ACT 186's passage during the last legislative session. The bill proposes several initiatives for improving the system of care for Vermonters and includes two allocations from the Home- and Community-based services Enhanced Federal Medical Assistance Percent funding to the Department of Disabilities, Aging, and Independent Living.

ACT 186 included creation of a Residential Program Developer, in which Julie Abrahamson has been hired within the Department of Disabilities, Aging and Independent Living (DAIL). It allocated \$500,000 to DAIL from the Home and Community based services to develop housing and residential service pilot planning grants in at least three regions in the state. It also requires DAIL to convene a 9 member steering committee of Self Advocates, Parents, developmental agency staff to provide advice and guidance as it selects the pilot planning grants. Julie Abrahamson is working with Jennifer Garabedian and the steering committee on the application for the grants.

ACT186 however is only the beginning of the path for our families.

I would like to explain our family's path for our daughter in exploring living situations since the age of 23.

Our First attempt was a Shared Living Provider's (SLP) home, which has been the typical, most "cost effective" model utilized in Vermont after the closing of Brandon in 1980's. The problem with this model is that this is basically Foster Care for adults with disabilities. At any time the SLP can decide they no longer want to provide care leaving the individual homeless. This is not the individual's home so there is no sense of permanence. Some of these SLP situations may be working, however, there's no one size fits all and individuals need to have a choice for living

situations that fit their needs and preferences. The following occurred to my daughter in the SLP model:

After living with the shared living provider for 6 weeks, I picked her up for a trip to the Great Escape Lodge. She had several bruising marks on both upper arms similar to fingerprints which she said were from one of the shared living providers and her clothing smelled, unfortunately, like bunny bedding. We removed her from the situation immediately. When we picked up her personal items, all her clothing and bedding smelled like cat litter and bunny's litter. The household had two cats and they kept two bunnies in cages in the kitchen. She never asked to return to their house.

Our second attempt lasted a year and a half at a Therapeutic living and licensed community. Our daughter is a unique individual, as we all are, and apparently didn't "fit" the model they wanted for their community. They blindsided us and our service provider requesting additional money to provide services. When our service provider was unable to increase payment, they asked that we purchase a home nearby, hire a Shared Living Provider to live with her, and continue day services with them. We chose to bring her back home for our economic reasons (not wanting to purchase a house) and for her safety. Since they still felt they could continue to provide daytime services, we felt that this issue was more financial rather than the "fit".

Presently, she is living in her own apartment with caregivers 24/7 hired by Champlain Community Services. We have found a model for her that makes her happy and feel thrilled that this is her special place that she calls her home.

Her first apartment was at the Fort Ethan Allen. Even though this was a Champlain Housing Trust affordable housing, we had to pay the majority of the rent for her from our funds since her only income source was SSI. She was on Section 8 housing list but was still possibly 5 years from being moved to the top of the list. After residing there for 9 months, she was notified that her apartment was to be converted into drug/alcohol rehabilitation. This actually was a blessing! This moved her up into Section 8 housing. The challenge came when we attempted to find affordable housing with 2 bedrooms (second bedroom needed for 24/7 caregiver bedroom) and within the price range identified by Section 8. We were into the last week allotted by the Section 8 to choose an apartment when we, luckily, found that Champlain Housing Trust had a brand new apartment building opening. She chose a unit that catered to her sensory issues on the top floor at the end of the hallway away from the elevator to give her quieter environment away from loud sudden noises.

This present model requires tweaking. There is a staffing shortage in all healthcare. We do not have full coverage in this 24/7 model and we as parents are frequently needed to cover when staff are out sick, on vacation or have quit. We can assist sometimes but we are only going to live so long. There's no available back up staff except for the program manager and my fear is that overuse of them will burn them out and we will be in worse shape for staffing. Several staff have had to work overtime for coverage and this increases the cost of care. Again the possibility is burnout and potential loss of staff.

We had a period over 6 months in a year between hiring two separate program managers and had 3 different program managers in a 13 month time frame.

Salaries are the number one reason there is a 24% vacancy rate of direct service providers. It is difficult to recruit and retain direct service workers when non-service wages continue to increase, some starting wages at more than \$20/hour.

What do we need for our daughter and others to address these issues:

- Staff need to receive an adequate living wage salary, benefits, and on-going training to get good people to care for our vulnerable adult children. Including yearly raises. Please support the Vermont Care Partners in their ask to increase Medicaid funding 10% to go directly to Direct Services Workers. Including a yearly rate review.
- Creative staffing and developing of living situations (housing) to meet the needs of various functionality of individuals to include service supported housing in affordable housing in our communities.
- Housing for individuals with developmental disabilities needs to be seen as a need equal to those individuals who are homeless because as families age, they will be living without their families' supports. Increase Available Section 8 housing vouchers to assist in funding access to housing. Including them in the millions awarded this year to create affordable housing.

As you advocate for funds remember these vulnerable individuals who need support to live in their communities. Please provide them with opportunities for future affordable housing and fund caregivers to provide services. Our family members deserve choices for stable housing as set out in the federal Centers for Medicare and Medicaid Services (CMS).

Thank you for your time and advocacy.